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Lessons Learned from Participatory Design in Dementia Care: Placing Care Partners at the Centre

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Abstract. In this paper we analyze the participatory design (PD) process of a health information technology (HIT) project. This project, AToM was situated in dementia care and involved partners from academia, industry and care. The analysis specifically focuses on the role of the care partners in the PD process. We will show that the conditions to enable 'good participatory design' were not fully met and we present a set of actions to prevent this in future HIT projects. Central to our recommended approach is placing the care partners at the centre of the PD project.

Keywords. participatory design, lay participatory design, care domain

1. Introduction

In 2008, one of the founding fathers of participatory design (PD), Pelle Ehn [1], provided a definition of PD which looked back on and forward to the legacy and prospective use of PD. *"Participatory design started from the simple standpoint that those affected by a design should have a say in the design process. This was a political conviction not expecting consensus, but also controversies and conflicts around an emerging design object. Hence, participatory design sided with resource weak stakeholders... and developed project strategies for their effective and legitimate participation."* In the early days of PD, the resource weak stakeholders were workers in factories whose work was affected by automatization and digitalization, changes they could not master. Workers were dis-abled in taking control of the design and implementation of the new tools in their workspace, as they were either not heard or not en-abled to raise their own concerns or desires. It was the task of the PD researchers to provide them with ways of participating in technology design that supported and included their perspectives and needs with all the other stakeholders (such as management or the developers). This early form of PD had some specific characteristics starting with the blurring of the borders of the designer and the end-user; with the latter becoming an active participant in the design process (from design recipient to design decision-maker) [2, 3]. Additionally, a form of shared practice and shared agency [4] between users and designers emerged. In the process of participation, (the aspiration of) equality [3], mutual learning [5], reciprocity and a transcendence of the users' own practices [6] became of importance as well. In 40 years, PD shifted from a political interest through democratic

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systems development in the workplace, to a more encompassing notion of accountability in technology design. With this shift, the resource weak participants are not only workers, but a variety of people such as inhabitants of a town, children, or caregivers. The latter being the focus of this paper, more specifically health professionals working in dementia care.

Many researchers, developers and designers have build expertise in working in a participatory manner together with actors in the care domain. Reflecting on one of our own projects, in which collaboration with health care partners was set up in accordance with the literature on PD in (dementia) care, we felt that the participation of care partners in the design and development of new tools in their own workplace was still suboptimal. This project, named AToM, focused on integrating internet-of-things technology in a setting of dementia care. As in any PD project, we strived to comply with certain conditions specific to PD. These conditions included searching for the above-mentioned common ground, aspiring equality, working towards mutual learning, reciprocity and transcendence. With these conditions we aimed to achieve a kind of 'good' participation. In retrospect, these conditions were not met, and perhaps even seem to be very difficult to achieve in Health Information Technology (HIT) projects in general. By not meeting these conditions, PD projects run the risk of creating imbalance in the care partners' participation and thus missing out on 'good' participation.

To further understand why exactly it is so difficult to meet the conditions of 'good' PD in the care domain, this paper analyses how the AToM project failed to achieve 'good' participation. The next section ("2. The AToM-project") gives an insight in the setup of AToM (who was involved, what was the initial goal, etc). Section "3. Evaluating the role of the care partners in AToM" provides a typology of design decisions and defines what 'good' PD can be. This is then used to analyse –using interview data from care partners in AToM– the design decisions and PD in the AToM project, identifying several disabling actors and elements. The fourth section ("4. Reflection on consequences for care") searches for causes of these disabling actors and elements and ways to overcome them. In a final section we briefly show how these 'ways to overcome' have been employed in another project called AtHome.

2. The AToM-project

The AToM project ('A Touch of Memory', 2011-2013) started from an interest in novel technology and care. The original aim was to explore how internet-of-things technology (the use of sensors, electronics, software and a network embedded in physical objects) could be employed to benefit the daily life and care of persons with dementia and their network of family, friends, (in)formal caregivers. The project setup was open and exploratory by nature, and tried to take initial first steps in taking the objects that are meaningful to persons with dementia and 'make them smart'. An example of such an object, which was used in the project to explain the concept to lay persons, was a smart walking cane that 'knows' that a person with dementia is going for a walk every day. It would be able to detect if this person is about to leave the house without bringing along the cane. The cane could then 'tell' the person to not forget to take it along. Consisting of 11 partners from academia (social scientists, interaction designers and IT developers), industry and health care, AToM's consortium also included two residential care organizations with specialized dementia wards. The main motivators for these care partners to join the project were a willingness to bring innovation to their

care facilities and the sector of dementia care in general, as well as being pleased that disciplines other than care were taking an interest in their work.

The AToM consortium strived for participation of all stakeholders (academia, industry, care and persons with dementia) in the design process. A series of participatory sessions using mapping kits (large maps and sticker sets) were used to involve persons with dementia together (see [7]) and caregivers were involved in ideation sessions and interface prototyping sessions. Preceding these, an ethnographic study tried to find meaningful routines, moments and objects to which the internet of things-technology could be beneficial.

Over the course of 2.5 years, AToM was funded by two funding bodies that had joined forces in a funding program that focused on multidisciplinary, demand-driven digital R&D. A variety of regulations stipulating the objective and ways of funding existed: societal but certainly financial valorization had to be the project's main goal; the effort of the academic partners should equal to those of the non-academic partners; the program provided full funding for academic partners and partial funding for non-academic partners; to get funding, non-academic partners had to 'prove' that their participation in the project was to result in an impact on (their) rate of employment, investments or added economic value to their organization and the region; etc.

The end result of AToM was a prototype of a smart mealtime app combined with a setup of sensors and electronics in a care home. The app detected patterns in what a 'good' meal experience for a person with dementia would mean. It combined input from caregivers ("How do you evaluate the meal time experience for this person?"; "How much did this person eat of the portion?"; etc.) with sensor data (level of ambient noise or temperature; number of toilet visits previous to meal time; etc.). All this data was combined with a database of previously entered and registered data. The app's data analysis aimed to support the team of caregivers to better understand the meal experience of individual persons with dementia in order to ameliorate meal time. When, for instance a caregiver would indicate that a person seemed to have lost their appetite over a period of days, the smart mealtime app could search for patterns ("When did this person lose their appetite before and were any of the conditions similar?"). The app would inform the caregivers about potential causes (eg. "This person is inclined to eat less when warm weather occurs"), supporting caregivers in a potential plan for action.

3. Evaluating the role of the care partners in AToM: 'good' participatory design and dis-abling actors and elements

The AToM-project became a point of reference for three participating researchers (a social scientist, an interaction designer and a design researcher – the authors of this paper) who, during AToM were responsible for the PD process. Since AToM, each of them continued working on similar HIT and design projects. In retrospect, they felt that the care domain in the AToM project could have had a higher level of participation. Looking back at the above-mentioned conditions of 'good' PD (mutual learning, aspiration of equality, and such), these seem to have not been met, despite the consortium's explicit intentions to do so. In what follows we analyze how decisive acts and elements affected the participation of the care domain in the AToM project.

3.1. Typology of decisions in a design project

Our analysis starts from a chronological map of the various meetings held between all or a number of project partners. The map also incorporates other important moments in the project (a workshop sharing insights from ethnographical work; the abandonment of a key partner; etc.) and elements such as reports of research tasks, chat conversations, encounters with persons with dementia, and information such as the location of a meeting, the members present, etc. All had a decisive impact on the project (sometimes in a minor way or in ways that were not clear at that time). It is to be noted that this information is of course limited to what the three authors had archived.

To categorize these elements, we use the typology of decisions as made by Bratteteig and Wagner [8]. They stress the importance of analyzing decision making throughout a design process. It is this exercising of power that disables or enables a group to be heard. Bratteteig and Wagner make a distinction between big decisions; two types of small decisions and non-decisions. Big decisions deal with values and concepts that provide a normative basis for the project and its participants. This, for instance, includes the fact that a project is participatory in nature. The implementation of these big decisions is what is seen as the small design decisions in a project. Such small design decisions are open for debate and their long-term effect is not always immediately clear. Bratteteig and Wagner distinguish two different types of small decisions: decisions internal to the project and decisions that need to be negotiated with the outside world, outside of the consortium. Decisions internal to the project can relate to the way meetings are set up and what each participant's role is. A decision that needs to be negotiated with the outside world might for example be the way participants are recruited or how your research acts are debated with ethical committees. The last category, the non-decisions, are given things that 'just happened', that the consortium has accepted without much discussion. A test location available to the consortium is a typical example of a non-decision. After our chronological mapping we re-categorized the decisive acts and elements using Bratteteig and Wagner's framework. This raised the awareness of the role of the different partners (and caregivers) in certain decisions. When we defined something as a non-decision for example, it indicated that this decision was non-negotiable. Who then 'benefitted' from this non-decision and who was kept silent? The same goes for talking about big decisions: when were the normative concepts and values set? Who took part in deciding these?

The mapping of decisive acts and elements gave an overview of what was considered as 'meaningful' to the project. The categorization based on the framework of Bratteteig and Wagner helped us in making explicit who was and was not involved at what point regarding the decisive elements. The next step is to focus further on this participation and set the 'boundaries' for an analysis of these decisive acts and elements in relation to PD. In what follows we first reflect on 'What is good participatory design'.

3.2. What is 'good' Participatory Design

Several authors have defined what can be seen as 'good' participation. Kensing [9] finds that good participation has three core qualities: access to information, resources (time, money) and the possibility and power to influence decisions. Kensing also refers to Clement and Van den Besselaar [10] adding that a proper method should be employed and a need for organizational and technical flexibility. Bratteteig and Wagner

[11] identify 5 elements that support assessment of how participatory a project was. Their analysis starts with (1) the PD result: how does the result empower users, e.g. to perform a certain thing they couldn't before or by giving them a voice. Second, they focus on the (2) user participation in creating choices, dealing with *"defining the problems that a design project should address and also indicate possible solutions"*. Next is the (3) 'see'/evaluate part of designing, which provides openness for participants to see and evaluate the intended artifact. Though not always possible, the next evaluator (4) is identifying the different design choices present. Finally, the 'making'-element, solidifies these choices (5), and lies mostly in the hands of designers, though non-technical ways of making might help to improve participation of participants from non maker-backgrounds. In addition to the aforementioned definitions, Huybrechts et. al. [12] stress the importance of transparency of information and documentation, the fitness of the applied participatory methods, tools and techniques, and their openness to be co-configured by participants.

Combining these different views on the quality of participation, we formulated a set of questions that help to define the quality of participation and formed the basis of our analysis: (1) How did structural elements (such as a project's proposal or funding opportunities) influence the participation? (2) Were the appropriate tools, methods and techniques used to allow for participation? (3) Which stakeholders were involved in defining the design problems, the way of participation, and were these stakeholders able to make suggestions to solve these problems? (4) Was the information available in the project transparent and the artifact (the different prototypes of the digital tool in AToM) open enough for all participants to participate in the making process? (5) And, finally, what are the participatory qualities of the end result?

When discussing the decisive elements in the AToM project that were mapped according to Bratteteig and Wagner's typology, these five questions became the tool for analysis. This analysis resulted in a series of provocative statements (eg. "The care domain was only a location of research, not a partner") that we presented in an interview to the project partners from the care domain. The statements served as catalysts for a discussion on how they, in retrospect, evaluated their participation and role. Two of the partners not only reflected on this specific project, but spoke out of their experience with other HIT projects. As these projects were similar to the set-up and goal of the AToM-project, these answers have been taken into account as well. Bert, Martha and Bea were the main contact points for the project at the two care partners. They attended consortium meetings and workshops. All were interviewed separately and the interviews took place almost three years after AToM ended. Bert is the director of quality and innovation in his care facility. His colleague Martha is the head nurse of one of the dementia wards. Bea is the physical therapist at another care facility. Other caregivers working at these care partners (psychologists, nursing assistants, nurses, etc.) participated in several of the project activities as well. Snippets from the interviews with the care partners were thematically clustered leading to six themes: 'usefulness to care'; 'imbalance and dominance'; 'language difficulties'; 'reflection vs pragmatism'; 'individual and organization lack of experience'; 'lack of interest in care'. The provocative statements resulting from the mapping of decisive elements were then reassessed using these clusters of interview data. Some statements were refuted (e.g. The caregiver as project lead), others were confirmed (e.g. The use of English is disempowering) or tempered (e.g. the fact that care partners did not apply for funding did not make them feel less appreciated, but would have helped to engage more peers in their organization) and new insights were raised (e.g. care partners felt they were par-

ticipating to give advice, but did not influence decisions). In the following section the results of this analytical process are described under five main categories.

3.3. Analysis of the provocative statements and the care providers responses

3.3.1. Role and function of the care partners

In the project setup, care was often perceived as a mere location of research. For instance, during the writing of the proposal, two design researchers chatted about the fact that a potential care partner dropped out a month before the funding proposal deadline. Their main concern was that they would lose a place to do their research, i.e. recruit and involve persons with dementia, caregivers, etc. In this sense, the caregivers were seen more as subjects of research and not as partners. Bert confirms this: *"When something needed to be tested, tried out or observed,... you (the research and industry partners) just said you would come and do it. (...) Hardly anyone asked whether it would be feasible for us, whether we wanted to do it or whether we found it to be a good idea."*

This applied to the care partners' involvement in prototyping sessions or other workshops as well. The care partners took part in prototyping or ideation workshops, but were excluded from deciding on the value, the setup and the way of executing these workshops. This is related to Bert's critique that within the project there was little room for the why-question: *"In the care domain we need a philosophical-ethical reflection on what we are doing. (...) You could easily see that the other parties were more involved in practical things, not in questions whether what we do is ok or should be done or whether there is a different way to do things."* (Bert)

3.3.2. Use of language in the project

The language used in the project deals with several elements. One of them is the literal language: due to the participation of international researchers, English became the lingua franca in meetings and other forms of communication. After several meetings we found out that using English was a problem for the care partners. As such, most care partners listened to what was said (in English), sometimes needed a translation, and, when they replied, did so in their native language. Jargon turned out to cause a similar threshold. Coming from a research background in technology development and design, the knowledge about technology and design terminology was evident to academic and industrial partners. For the caregivers, however, most of these terms were not easily understood: *"The technical jargon! That was far removed from my own personal context. I could see engineers talking about the things they were making for us, and I didn't understand what they were saying. (...) We live in separate worlds."* (Bea)

The language of the project also related to the tools used. The methods and techniques employed during the workshop-moments with the caregivers were seen as empowering, as Bert indicated *"they really helped our staff to understand the potential of such a project... we were working on something new, something to make our daily work better. And I could have a say."* However, transfer of knowledge happened mostly via written reports (deliverables) and PowerPoint™ presentations following the structure enforced by the funding program (using work packages and tasks, the allocation of man-hours versus tasks, etc.). This way of working, typical to research contexts, turned out to be an element of exclusion for care partners as Bea illustrated: *"I didn't know where to start! I really had to find my way into everything. I had no idea what was intended when we needed to deliver something at a project's meeting."*

3.3.3. Perceived added value of the care domain - structural limitations

A reflection on how the added valued of the care partners in the project was perceived by the other partners starts with the literal monetary valuation of the care partners' participation, but also how the participation of the care partners was valued in project meetings or the project's result. The care organizations did not file for funding as the funding program only supported partners whose participation in the project would result in a substantial (proven) impact on their rate of employment, investments or economic added value; requirements that are difficult for care organizations to comply with. The care partners didn't perceive this as a big barrier to participation, however, as Bea and Bart indicated, it would have potentially helped the project if more resources and time had been spent generating more engagement on the work floor.

As most other project partners did apply for (and received) funding for their efforts in the project, financial disparity between the different project partners played a role on a different level. One of the funding requirements of the project program is that the effort of all academic partners (in terms of person months) equals the effort of all other partners. During the project, one of the industrial partners decided to stop, which had major implications on the consortium, as the efforts of the academic partners were now higher than those of the non-academic partners. One of the remaining industrial partners proposed to 'save' the project on the condition that the research, design and development activities and aims be more 'attuned' to their research goals. At this point in the project, the final design concept was not yet definitive. Based on concepts resulting from a participatory ideation workshop several design paths were still open. As the project needed to cater to the ambitions of this 'saving industrial partner', these other design paths were abandoned. This abrupt shift was a disappointment to the care partners. As Bert indicated, the final outcome of AToM was definitely not useless (on the contrary), but the abandoned ideas were felt to potentially be more useful (as they were more patient-centered, directly influencing the patients' well-being). Thus, the way the funding program was set up restricted the project's content and outcome.

3.3.4. Making their participation matter

The care partners were also not involved in the setup of the funding proposal in which the fundaments for the project were laid out. At the start of the writing process another care organization was asked to join, but neglected to continue as they found the initial draft of the proposal lacked "commitment", giving them little "return on investment". This links to a critique by the participating care partners on their own return of investment. The initial enthusiasm of the care organizations in the project diminished once they realized that the end-result of the participation would not be a finished product, but a prototype or (even though this was repeatedly communicated to them before the start of the project). The care partners also indicated that the project was felt as belonging to 'them' (the academic and industrial partners), not 'us' (the care partners): *"Most of the times (during project meetings) the industrial partners and the research partners seemed to be on the same wavelength. In my view, you had a goal and a plan and a way of carrying out that plan. Our (the care organizations') role was to share a bit of our expertise and ideas"* (Bea). Martha is even more critical saying the care partners *"underwent and endured whatever you had in store for us"*.

It was also felt that once the project went into the design phase the vision of the care partners didn't matter. Sometimes the care partners really wanted to steer the design process and outcome towards being more functional but failed to do so: *"When I*

made some suggestions to adapt the things that were made in this or that way, I sometimes just got a plain 'no, that's not possible'. Of course I don't have the knowledge to tell them otherwise. (...) Industrial partners sometimes made small decisions and were very rigid in wanting to change them. They couldn't understand that these small changes make the difference between a design being useful or useless." (Bert).

One example of how the vision of the care partner was undervalued relates to the technology used. As two of the industrial and academic partners had smartphones and tablets at their disposal, this became the preferred technology despite the fact that the care partners expressed resistance against the use of smartphones as they didn't see it fit in a workplace (not practical as a lot of tasks demand the use of both hands); as caregivers aren't allowed to use smartphones in the workplace and as some individual caregivers might not feel capable in using a smartphone. This seemed to be characteristic of the role of the care partners in the project: the care partners defined it as the 'project's imbalance' with the academic and industrial partners' predominance on every decision. Bert felt that they were left out not only in the big decisions (which he perceived as already decided upon immediately after the project started), but also in the small decisions. He felt this was due to his lack of technical knowledge: *"I guess there were several meetings where we were not present, probably because these meetings were too technical. But then in a next plenary meeting we heard that decisions were made and could not be reversed, despite the fact that we -coming from care- didn't think those decisions were good ideas. Our value in such a setup is lost.*"

3.3.5. The care partners' organizations' identity

To engage in and devote time to projects out of the traditional context of caregiving is quite uncommon in most care organizations. The partners' staff deployment in AToM illustrated this. While research groups and companies have employees whose job it is to work on projects and to do research, this is an uncommon task to most employees in care organizations. This became evident during project meetings in which from one organization a managing director would participate and from another it would be the physical therapist or a psychologist attending. The participation of someone who on a daily basis works as a caregiver for persons with dementia also had practical implications. If, for instance, a nurse was to participate in one of the project activities, they had to be replaced in already understaffed wards. As a result, during the project meetings little participation of people active in the care practice on a day-to-day basis could be guaranteed. And, as Bea indicated, this had consequences for the engagement of all care staff: *"I had no idea how to handle this, neither did any of my colleagues. In fact they didn't really care to bother. (...) I think, in the end it became a bit 'Bea's thing' and less something from our dementia ward."*

3.3.6. Summary

In summary, PD methods herald collaboration and actively support the enabling of participants to be part of decision-making in the design process. Retrospectively, both the authors and the care partners see that care partners were dis-abled, despite the fact that PD methods were used. A combination of disabling actors and disabling elements seem to be at play here, with different elements and actors having an influence at the same time. Not participating in the writing of the funding proposal is a consequence from there not being a tradition in care organizations to write proposals ('The care partners' organization's identity'), but the fact that the language used is typical to re-

search contexts ('Use of language in the project') also contributes to this disabling. As these elements seem to be intertwined, so are the disabling actors. We see three disabling actors, with the funding program being the first. As it was difficult to prove for the care partners how their participation would have a substantial impact on employment rate or lead to economic added value to their organization, no financial compensation was foreseen. As such, the funding regulations of the funding program may have placed the caregivers in a secondary position. The funding program also required that the combined efforts of the academic partners equaled the combined effort of the non-academic partners. When in the middle of the project, an industrial partner dropped out, their role was taken over by another industrial partner who took a much larger stake than was originally the plan. This influenced the work of the partners, the remaining design decisions and the end result and, in AToM, the deployability of the design results for the care partners. Next to this, the other project partners seem to have failed in giving the care partners a voice. When meetings were being held in a language that care partners did not master, or tools used that were unfamiliar to them, they did not negotiate a different way of working. Regardless of the lack of funding and despite the participatory nature of the proposal, the other partners did not take the care partners fully into consideration in the setup of the funding proposal which resulted in their failing to have their voice heard even before the start of AToM. Surprisingly, the care partners themselves did not step to the fore to claim an active role in the project's decision process either. Sometimes, as in the case of Bea, a lack of experience with research projects was partly the cause. However, both Bert and Bea didn't feel that their level of engagement required them to be active in discussions. More than once in the interviews both used the term 'your' project, meaning ownership from the industry and academic partners, and not 'ours', meaning ownership of the care partners and all partners. Bert fiercely expressed his discontent with projects such as AToM where there is little tangible to be gained from care partners' engagement and questioned if they should have spoken up or taken a larger role.

4. Reflection on consequences for care

As several disabling actors and elements were identified, the question remains why these were at play. In this section we will elaborate on potential causes, based on both suggestions the care partners made during the interviews as well as on the analysis of the decisive elements by the authors. We will not answer all causes for the disabling in the AToM-project as these can not be met through an intervention by a researcher or a designer: funding opportunities that do not (only) take economic impact and employment rate as prerequisite to receive funding are very rare, neither can one fully escape a funding body's jargon or rules of reporting (using work packages reports and the like). Next to that, to allocate staff to research is uncommon to most care organizations and requires a change of culture of (smaller) care organizations to take on research as a necessary and worthwhile investment.

Our analysis starts from the work of Jung Joo Lee [13] who explores the cultural fitness of certain innovative design methods from a cross-cultural perspective. She pleads for cultural sensitivity in the use of methods, stating that a method typical to a certain cultural or ethnic group, will not work when applied to another group. Moreover, she pleas against the idea of methods as recipe-like tools, and the researcher as *"an objective observer, and culture as a pre-existing entity where members of the cultural*

group are characterized by traits and averages" [13, p. 7]. While she is working on human-centered design methods and defines culture as something related to nationality or an ethnic group, her work is also relevant in the analysis of AToM. If we perceive the care domain as a culture, in the line of Lee, the authors, being the researchers responsible for PD, recognize in retrospect that they have failed to fully understand and act on the culture typical to the care domain. As a result, we became a disabling actor ourselves, as we failed to find common ground or to bridge our culture with the culture of care. Lee focuses on several elements that can help to overcome this cultural difference. In situated design work, designers can understand what matters in a local context and will in this way gain 'local sensitivity'. What Lee suggests is that it is necessary to have an openness in the methods we use when involving the culturally *other* (the care partners in the case of the AToM project) and that it is in our relationship with the care partners that collaboration thrives. Furthermore, each design situation needs to be evaluated and tackled individually. In practice, local sensitivity will not only be gained through typical design work (in the form of workshops or prototyping sessions), but also through meetings, informal contact and conversations, etc., i.e. in the *"designer's practical work and unofficial interactions with users"* [13, p. 103].

Lee is not the only one to point to the importance of this design work done at the 'backstage' of a design project. Dindler and Iversen [14] talk about the difference between front stage and backstage in design. Activities such as workshops or prototyping sessions are seen as front stage, while activities such as modeling or sketching and creating strategic partnerships partners are typically backstage activities. Backstage activities on the relational level include 'spending time', 'creating attention' and 'trying to build common understanding'. These types of activities are not found in scenario-based or well-defined and -planned actions, but through conversations, meetings, mails, etc. and they will help the relational work of a design process. This relational work is important for the success and sustainability of a design project. Backstage activities also aid in creating alliances and thus play on a strategic level. Dindler and Iversen notice however that in most projects this relational work is not seen as a critical element of the research activity. What probably occurred in the AToM project, is a failure to perceive the importance of the backstage of projects and the way back- and front stage can mix. For example, care partners were enthusiastic about the interface prototyping workshops and talking about their work with the researchers during lunch, but they figuratively 'lost their appetite' during decisive meetings where the progress of the project was discussed.

When being critical towards the way the care partner is valued in a participatory project, what has been coined as the 'cult of expertise' [15] seems relevant. The cult of the expertise notes the fact that expert knowledge is heralded in a design project and leads towards a power imbalance between the expert participant (those who have expertise in PD or design and development in general) and the lay participant (whose expertise lies on another level, for example in providing care for persons with dementia). Tandon [16] talks about the ambiguities of participatory research and relates this to the fact that though ideologically participatory researchers wish to abolish the separation of roles (between those of researcher and those of 'ordinary' participant) it can not do so as most participatory practitioners originate from a classic knowledge system (and tradition) that focusing on roles and underlying divisions. What happens next is what Freire calls a 'cultural imposition' [17] where the culture of the expert, their way of working, value patterns, etc. is imposed on the culturally *other*. Mushtaq & Hall [15] analyzed a HIT project in the global south and identified how the cult of the expertise

comes into play as, for example, caregivers are only partly allowed in collaborative processes having a say in decisions on interface design, but not on more 'big' decisions such as the type of technology to be used. In the AToM-project we see, again in retrospect, how caregivers were set aside. Being the non-experts in design and development lead other partners to perceive the opinion of the care partners as less relevant and the technical expertise of the designer and developer as the dominant voice. Mushtaq & Hall ask for a type of 'lay participatory design': a form of PD that leaves the creating/designing mostly in the hands of and driven by the knowledge of ordinary people, letting them having the dominant voice, placing them central in the project.

Though the AToM project was intentionally participatory of nature, we, like Mushtaq and Hall, unknowingly did not let the care partners in on the larger discussion. Tandon reflects on this gap between intent and practice suggesting that self-reflexivity is key to avoiding this gap. In this way, one can try to dissect whether there is a form of cultural imposition and whether the cult of the expertise is too present. Ertner, Krage and Malmborg [18] focus on this self-reflexivity in PD. They see how inequalities in a design process can sometimes be employed unconsciously as the research practitioner *"represents a discursive power which may reduce the users' possibility in achieving influence"*. They therefore suggest a reflexive practice on how assumptions and knowledge will define methods, categories and interpretations. If we take their analysis as our starting point we should be critical towards our ways of setting up meetings or having the caregivers involved in the design process as a counterpart for the (unconscious) unequal shaping of participation through a dominant position of the expert participatory practitioner. A framework for this self-reflectivity can be found in the work of Ramia Mazé. Mazé [19] discusses how the framing and staging of a (participatory) design process is decisive for the role participants get in the process and for the design outcomes and especially for what the effects are on existing power relations. Mazé differentiates between materialities, temporality and territories. With the lens of materialities one can look at how the use of human and non-human materials will leave out or include certain voices in the design process (how, in AToM, the use of English as the main language of communication, and work package reports gave a voice to or muted the voice of the care partners). Temporality deals with who was involved and when in the design process (when did we invite the care partners and when were they left out). Territories deal with the value of the locality: who owns the place where design takes place and how 'normal' or 'strange' this location is for the participants involved (how did the choice of the project partners of being or not being immersed in the care context influence the project). All three have an influence on the way design enforces or reproduces division and includes or excludes certain groups from the design process and can be used as concerns raised before and during a project.

As we have defined these potential causes, a next step is to take concrete actions to overcome them. From Lee and Tandon we take away the importance of perceiving the care domain as culturally different from the culture of the other partners in the design process. In order to better understand the culture of care, we have to work towards a local sensitivity. This sensitivity can be gained through a situated way of working, in the context of the care domain. This situated way of working, (action 1) uses the location of care as the main research and design base and places the care partners central in the project. This helps to support lay PD by giving care a dominant voice in the shaping of the participation. In doing so, we (action 2) use the language and tools of the care domain. As (action 3) equality and mutual understanding and learning is key in 'good' PD, we try to provoke this mutuality through switching roles, having the researcher and

designer becoming caregivers and vice versa. To provoke this and enhance participation we (action 4) stimulate engagement, by making sure that every participant has something at stake. Next to this, both Lee and Iversen & Dindler shed light on the importance of the backstage of a design process. In retrospect, the AToM project did not sufficiently perceived these backstage activities as important and mostly focused on the front stage of the design process. These front stage activities (the prototyping workshops etc.) were perceived as positive by the care partners, likely because these were explicitly open to their participation. However, we failed to see that these backstage activities were as important to the project's process and end results as those taking place in the front stage. A next step would thus be to see (action 5) informal contacts as essential to the research and design process. A last element is to be reflexive towards the risk of 'cultural imposition' that might happen in these type of care projects. The work of Mazé provides a critical focus and can be used both in the setup as well as during a project as it provides a reflexive lens. A 6th and final action therefore would be to use the questions on temporality, materiality and location in both the setup as well as during a project. In the final section we will look at how these actions were put into practice in the AtHome project.

5. Put into practice – The AtHome-poject

AtHome (2014 – ongoing) researches how designerly practices can enhance the feeling of home for a person with dementia in residential care. The project tries to change the way care is involved using the lessons learned in AToM. It does have a different setup involving fewer partners and, unlike AToM, it has an aim that goes beyond economic valorization. We will discuss how this project put into practice the different actions outlined above. Central to these actions is to put the care domain at the centre of the project in order to gain a local sensitivity. Needless to say however, this is not a one-way action. To strive for equality (in participation), reciprocity and mutual learning also asks the caregiver to move towards the other parties involved.

5.1. The location of care becomes the central research and design location

In AtHome, researchers and designers work inside a care centre within two specialized dementia wards for a minimum of one day a week. This integration is a physical one, taking place in the residents' rooms, common rooms and offices at the dementia ward. The researchers and designers take part in the daily life of work and care: having lunch with caregivers, singing together in the dementia choir, joining the caregivers at their yearly party and lending a hand when the Christmas tree is set up. This embeddedness, or becoming part of the fabric of the care environment, redefines the role of the designer or researcher from a distant other to 'one of us'. It moves the designer/researcher from an objective observer to an involved actor: the researcher is no more a mere passer-by but is 'part' of the care environment. Being present in this environment provides the researcher a chance to gain more empathy for the care sector through immersion. For the caregiver, there is less of a threshold to vent critique or voice a concern as they are not discussing things with a distant person, but with a familiar face. This became evident during a discussion between the caregivers and the researchers about a methodological experiment (wanting to set up performance workshops with family of the persons with dementia which the caregivers thought would be too time consuming

for the family). A mutual understanding, however, started to grow as the researchers became aware of the fear the caregivers had that too much time would be spent on the creation of abstract 'things' (methods) that would not lead directly to tangible results (beneficial to the daily life and care in the facility). The caregivers for their part, were intrigued by stories about conferences and paper writing (the importance for the researchers to have innovative and reflective actions) and began to understand that the researchers were not only present to 'just' create things.

5.2. Use the tools and language of the care domain

One of the central reasons for taking the care centre as the core location of the research and design project is to adopt the tools and language used in the care context. This begins with the timing of these meetings. Apart from a coordination meeting with the ward's psychologist, the discussions about our designs take place during monthly status updates or trimestral educational workshops; making design 'just another agenda item' next to an evaluation of the washing routine or a discussion on the best practices to avoid restlessness. In this way, discussing design becomes an everyday thing, natural to the existing context of care and work.

It also has had another side effect. After two years of working together with the researchers-designers, the caregivers also started to define the items on the agenda which dealt with research and design; taking the lead and making the reports of these meetings. This slowly shifts the project's goals and aims from design interventions directly aimed at the person with dementia to design acts aimed at the caregiver (and indirectly at the person with dementia); creating less expert-led design and instead more lay participatory design.

5.3. Create mutual learning and understanding through switching roles

Becoming immersed in the daily practice of care had the researchers-designers keeping company with a person with dementia in the common room, joining them at the hairdressers, helping care staff during mealtime, etc. In doing so, the researchers-designers learned 'on the job' about the caregivers' activities, about dealing with persons with dementia and about the role design can play therein. This included understanding the necessity for design tools to integrate in the day to day routine; the importance of evangelists who motivate their peers on the work floor; the lack of technical expertise and resources; the creative potential of caregivers to 'design' their own solutions to practical problems; etc. Conversely, the caregivers took small steps into the terrain of the designers. Next to the 'traditional' prototyping workshops, caregivers became part of the (physical) making process, as part of this is integrated in their daily work routine (gluing together prototypes, sending in suggestions on what the best way would be to capture a 'scent', etc.) and learning to create, repair or adapt the artefacts in a nearby FabLab. This mutual learning goes further than learning new skills, it goes so far as to see one's own profession with different eyes (eg. 'How would a full-time designer be beneficial to a care organization?'; 'What can a caregiver learn from the way a designer perceives as ideal care to a person with dementia'). In this way, this switching of roles helps to transcend one's own practice.

5.4. Stimulate engagement

In a participatory setup the question 'what is at stake and to whom' is essential. As both Bert and Bea indicated, without having something at stake and without being sure of a clear return on investment, participants are at risk of losing engagement. The logical consequence of the way caregivers, researchers and designers are involved forces each to make sure the right balance between 'getting something out of it' and making sure the other party 'gets enough out of it' is found. In practice, in AtHome, this means amongst others that each research and design step needs to balance the exploration in methodological experiments and the creation of innovative and aesthetic artefacts (the researchers' and designers' stakes) on the one hand, and artefacts that functionally support the day to day practice (the caregiver's stake) on the other hand. In doing so, both parties involved feel that what is done is beneficial to both.

5.5. Informal contacts are essential parts of the research and design process

As can be understood from the interviews with the caregivers, much is left unsaid in a meeting room, and this is due to several reasons (lack of engagement, feeling left out, feeling of not having enough expertise, etc.). To avoid this, we tried to tap into the conversation of the informal moments. Spending time at the coffee machine, going for lunch in the cafeteria, talking about newborn babies and renovations in recently bought houses has provided a base for openness. These backstage, informal discussions with caregivers provide moments for them to share their doubts or expectations about a certain design beyond the 'official' research and design topics in meetings.

5.6. Question temporality, location and materialities

In the AtHome-project we install regular moments for reflection with the dementia ward's psychologist. During these moments Mazé's elements of reflection are at play as implicit guidelines of our conversations. This leads us to reflect on the timing of meetings, making sure that the night shift can and wants to be present (temporality); that meetings are held – depending on their status – in the more formal general meeting room or in an informal setup in a corner of the dementia ward (locality).

6. Conclusion

In this paper, we have analyzed what role the care domain plays in PD of HIT. We see PD projects happening in a care context, but despite all good intentions, we notice a difficulty in involving the care domain in what can be called 'good' PD in which among others equality, mutuality and reciprocity are key. This paper has analyzed what disables the care domain and provided a series of actions to enable the participation of the care domain. What is essential is to place the care domain central in the project while taking on their tools and language and having the care context as the central location of the design and research activities. Doing this can lead to an engaged and close collaboration between care and other partners based on mutual understanding of each others' goals and roles. Future research will have to evaluate these ways of overcoming disabling more systematically and look for ways to find a balance between the

culture of care and the culture of the research/industrial partners, taking into account practical issues such as budget and time; the perspective of the care organization and their openness towards 'external parties' and, finally, from the perspective of the designer or researcher, the willingness (and competence) to step out of their comfort zone into the context of care.

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